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Incorporating qualitative evidence in clinical practice guidelines: a Scottish perspective.

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Incorporating Qualitative Evidence in Clinical Practice Guidelines: A Scottish Perspective

Kay Cooper[1,2] PhD, Pamela Kirkpatrick[1,3] MSc, Sarah Florida-James[4], MSc

1 Scottish Centre for Evidence-based, Multi-professional Practice: A Joanna Briggs Institute Centre of Excellence, Robert Gordon University, Aberdeen, UK

2 School of Health Sciences, Robert Gordon University, Aberdeen, UK

3 School of Nursing & Midwifery, Robert Gordon University, Aberdeen, UK

4 Scottish Intercollegiate Guidelines Network, Healthcare Improvement Scotland, Edinburgh, UK

k.cooper@rgu.ac.uk

Abstract

This article provides an overview of an approach to incorporating a range of evidence, including qualitative research findings, that the authors piloted when developing a clinical guideline on epilepsies in children and young people. We describe methods used for incorporating literature types not usually included in Scottish Intercollegiate Guidlines Network (SIGN) guidelines, including critical appraisal, and establishing dependability and credibility of

qualitative findings. We highlight limitations encountered and make suggestions for future work.

Key words

Guideline development, Qualitative evidence, Mixed methods

Conflicts of Interest

The authors have no conflicts of interest to declare

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Background

Guidelines have traditionally relied on evidence form quantitative studies to make recommendations for clinical practice. However, the use of qualitative research as an evidence base for generating recommendations has increased in recent years.[1] This is due to a range of factors including: guideline developers policies paying closer attention to patients' and carers' perspectives;[1] increasing numbers of guidelines on chronic conditions, where patients' needs are important;[1] and decision makers increasingly wanting evidence relating to acceptability and feasibility of interventions in addition to traditional measures of effectiveness.[2]

Lewin and Glenton suggested that the growing use of qualitative evidence to support decision making heralds the start of "a new era for qualitative research";[2] this view is supported by the use of qualitative evidence by several key guideline development organisations including the

World Health Organization (WHO), National Institute of Health and Care Excellence (UK), and the Swedish Public Health Institute.[2]

The Scottish Intercollegiate Guidelines Network (SIGN) has been producing evidence-based clinical guidelines for use in the Scottish National Health Service since 1993.[3] SIGN is currently developing a guideline on epilepsies in children and young people. During systematic literature searching it became clear that two of the guideline's key questions could not be addressed by quantitative evidence alone. We therefore piloted an approach to incorporating a range of evidence, including qualitative, in the development of recommendations for these key questions. The approach was informed by that taken by Coombs et al[4] but adapted to our specific circumstances. Here we provide an overview of this approach and suggestions for future developments.

Aims

To pilot the integration of a range of evidence sources, including qualitative research, in the development of a SIGN guideline on epilepsies in children and young people.[5]

Approach taken

Three core principles underpin SIGN's methodology: (i) guidelines are developed by multidisciplinary, nationally representative groups; (ii) literature is systematically reviewed and critically appraised, and (iii) recommendations are explicitly linked to the supporting evidence.[3] At the time of writing, SIGN key questions were generally formatted as a quantitative PICO, and literature searches framed to identify quantitative evidence.[7]

In keeping with SIGN methodology the guideline development group, which comprised healthcare professionals, lay representatives and academics, identified several key questions to be addressed. Two questions in particular were challenging to answer using quantitative

evidence: (i) the process by which transition from paediatric to adult services should take place, and (ii) when, where and how discussions about sudden death in epilepsy (SUDEP) should take place.

For the first key question (transition), systematic literature searching identified a high quality systematic review on transition from paediatric to adult services,[8] in a range of chronic conditions but not epilepsy-specific. The search also identified a range of other literature sources including scoping and mixed methods reviews, cross-sectional studies and a largely descriptive article. These would not traditionally be incorporated in a SIGN guideline; however, they contained evidence relevant to the key question and in the absence of epilepsy-specific evidence, the guideline development group felt it was important to include them. We applied Joanna Briggs Institute (JBI) critical appraisal tools to the cross-sectional and descriptive studies.[9] We however found a lack of critical appraisal tools specifically for scoping and mixed-methods reviews and were unable to formally grade their quality. Due to the inclusion of a variety of evidence sources it was possible to make conditional recommendations and good practice points relating to transition for children and young people with epilepsy, which would not have been possible if only high-quality quantitative evidence was eligible.

For the second key question (SUDEP), the systematic literature search identified mostly qualitative studies on patients', family members', and healthcare professionals' perspectives of when, where and how discussion should take place. Following initial review of the literature, the guideline development group modified the PICO to a qualitative PICo format[10] and conducted a second search of the literature in order to be comprehensive. A qualitative synthesis was initiated[11] (ongoing at the time of writing), and a further two qualitative and one mixed method studies were identified as relevant to the guideline but outwith the scope of the qualitative synthesis. These three studies were critically appraised using JBI tools[9] and the first

step of the JBI ConQual approach[12] was used to establish dependability and credibility of these individual studies. With this approach it was possible to make a conditional recommendation regarding SUDEP discussions at draft guideline stage; this may however be modified once the qualitative synthesis has been fully conducted.

Discussion

In this pilot we were able to integrate a range of evidence sources, including qualitative evidence, in the development of a clinical guideline on epilepsies in children and young people. Our approach to critical appraisal and grading the evidence was informed by JBI systematic review methodology; we are confident that this brought rigour to the guideline development process. However, our approach is not without limitations. Inclusion of qualitative evidence, in the absence of existing qualitative systematic reviews, is a substantial undertaking for a guideline development group. Adequate time, resources and expertise needs to be allocated for the conduct of novel qualitative syntheses alongside the guideline development process. During development of this guideline a series of articles on the GRADE CerQual (Confidence in the Evidence from Reviews of Qualitative Research) approach was published,[12] and CerQual is increasingly being used by guideline developers such as the WHO. GRADE CerQual will be applied in our ongoing qualitative synthesis on SUDEP discussion, which will in turn be incorporated in the final guideline. Finally, we were unable to apply a structured approach to critical appraisal or determining confidence in the findings of some other types of evidence (scoping reviews, mixed methods reviews).

Conclusions

We believe the inclusion of a range of evidence sources has enhanced the guideline development process discussed here. Without this evidence it would be difficult to make

recommendations for clinical practice on two important aspects of epilepsy in children and young people; with this evidence the perspectives of patients', family members' and healthcare professionals have informed the guideline (in addition to the perspectives of lay members of the guideline development group). There are still some limitations to overcome in order to fully integrate this range of evidence in guideline development methodology, and of course, the extent to which the recommendations will be easily interpreted and implemented by the clinical community is as yet unknown.

References

1. Tan TPY, Stokes T, Shaw EJ. Use of qualitative research as evidence in the clinical guideline program of the National Institute for Health and Clinical Excellence. Int J Evid Based Healthc 2009; 7: 169-172.

2. Lewin S, Glenton C. Are we entering a new era for qualitative research? Using qualitative evidence to support guidance and guideline development by the World Health Organization. Int J Equity Health 2018; 17: 126.

3. Scottish Intercollegiate Guidelines Network [online]. Available from: https://www.sign.ac.uk/who-we-are.html

4. Coombs MA, Davidson JE, Nunnally ME, Wickline MA, Curtis JR. Using qualitative research to inform development of professional guidelines: A case study of the society of critical care medicine family-centered care guidelines. Clinical Investigations 2017; 45: 8: 135201358.

5. Epilepsy in children guideline consultation draft. Scottish Intercollegiate Guidelines Network, Edinburgh, 2018 [online]. Available from: https://www.sign.ac.uk/attend-an-event.html

6. Guyatt GH, Oxman AD, Vist GE et al. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. BMJ 2008; 336: 924.

7. SIGN 50: a guideline developer's handbook. Scottish Intercollegiate Guidelines Network. Edinburgh, 2015 [online]. Available from: https://www.sign.ac.uk/sign-50.html

8. Campbell F, Biggs K, Aldiss SK, et al. Transition of care for adolescents from paediatric services to adult health services. The Cochrane database of systematic reviews 2016;4:Cd009794.

9. Joanna Briggs Institute Critical Appraisal Tools, Joanna Briggs Institute, Adelaide, Australia [online]. Available from: http://joannabriggs.org/research/critical-appraisal-tools.html

10. Lockwood C, Porrit K, Munn Z, et al. Chapter 2: Systematic reviews of qualitative evidence. In: Aromataris E, Munn Z (Editors). *Joanna Briggs Institute Reviewer's Manual.* The Joanna Briggs Institute, 2017. Available from https://reviewersmanual.joannabriggs.org/

11. Cooper K, Florida-James S, Kirkpatrick P, et al. Discussing sudden unexpected death in epilepsy (SUDEP) with children and young people with epilepsy and their parents/carers: a mixed methods systematic review protocol. PROSPERO 2018 CRD42018110295 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018110295

12. Munn Z, Porritt K, Lockwood C, Aromataris E, Pearson A. Establishing confidence in the output of qualitative research synthesis: the Conqual approach. BMC Med Res Methodol, 2014; 14: 108.

13. Lewin S, Booth A, Glenton C, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. Implementation Science 2018, 13(Suppl 1):2